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ABSTRACT

Intended for professionals and parents, this monograph focuses on the service needs of young children with cerebral palsy. Section I presents an overview of cerebral palsy, including etiology, incidence, and history of management. Section II describes service needs in the following areas: prevention; early identification; treatment; the interdisciplinary team; primary, secondary, and tertiary care; community support services; links with educational services; and training for health professionals. Section III discusses coordination of services in the context of decision-making and prevention planning. A short appendix lists references for further reading. (JW)

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The Early Needs of Children with Cerebral Palsy

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A Comprehensive View

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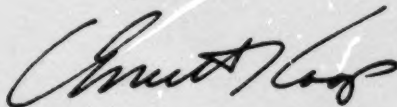
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Preface

Assuring the most appropriate environment for care of the disabled child is a major concern of this administration. Whenever possible, that environment should be the community, with the child surrounded by a loving, caring family. To create this supportive climate, the family must be afforded resources from both the private and public sectors. Built on the inherent strengths of the child and family, this support system can provide the necessary environment for optimal care.

With this support system in place, we must be mindful that services for disabled youngsters are greatly enhanced when they are coordinated by the health care provider responsible for overall case management.

This series of monographs, developed by the Division of Developmental Disabilities at The University of Iowa in consultation with the Division of Maternal and Child Health of the U.S. Public Health Service, promotes the welfare of these children and their families. The Office of the Surgeon General is deeply appreciative of and responsive to the concerns and purposes represented by this series of monographs.



C. Everett Koop, M.D., Sc.D.
Surgeon General

Introduction

This monograph is part of a series which deals with comprehensive services to children with disabilities. The first in the series, *The Needs of Children with Disabilities: A Comprehensive View* offers an overview of the history of health care of children with disabilities and presents a model which will allow the reader to view the role of health care services as part of the child's total service needs. Other monographs in the series, such as this one, *The Early Needs of Children with Cerebral Palsy: A Comprehensive View*, focus on the service needs of children with a particular disabling condition.

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These monographs are intended for people concerned with the planning, promotion, and delivery of services to children with disabilities. They are not meant to serve as guides to the specific content of therapies for professionals involved in direct care, but rather to promote understanding of the major issues related to delivering that care. Over the past two decades, new coalitions of people with disabilities have become articulate advocates of their desire to lead productive, participating lives. Advocacy efforts have led to legislation which defines and protects the civil rights of disabled persons, resulting in new and expanded health, education, and other service programs.

It is now recognized that children with disabilities have health care needs which are similar to those of so-called normal children, and it is not necessary, nor is it desirable, to separate or treat them apart from the rest of society. For a number of years the trend has been away from maintaining children with disabilities in an institutional setting and toward creating less restrictive environments for them within their own communities. Through federal legislation, handicapped children have attained the right to a free appropriate

public education and related services which may be required for them to benefit from special education.

The Federal Maternal & Child Health (MCH) Program has had a major role in promulgating the philosophies of prevention, early identification, and intervention and continues to place emphasis on a developmental model of interdisciplinary comprehensive care in a family-centered context. The program recognizes that disabled children with their families generally require long-term assistance from medical, social, special education, habilitative, vocational and community service professionals. This total care concept is essential to the provision of comprehensive services to children with special needs.

The reader will note that the terms **disabled** and **disability** are not used interchangeably with **handicapped**, or **handicap**, as is often the case. While some would argue that the words can be used identically, the authors of this series want to make the semantic distinction for social and philosophical reasons. A **disability** is a condition which limits some physical or mental functioning of the individual. A **handicap** is an obstacle which society, or sometimes the disabled individual, places in the way of accomplishment. In the past, society has handicapped individuals with disabilities by its limited view of their potential for independence and social contribution. It is the purpose of this series to provide the health care community with a broad understanding of the services children with disabilities need to keep from becoming handicapped.

The Division of Developmental Disabilities would like to thank the experts who kindly reviewed the draft documents. This monograph was reviewed by Murdina Desmond, M.D., Baylor College of Medicine, Houston, and Ruth Lencione, Ph.D., California State University, Northridge, with our thanks.

Special appreciation must go to clinicians Loretta Knutson Lough, L.P.T., Christy L. A. Nelson, O.T.R., and Patricia D. Keesee, CCC-SP, Richard T. Huber, graphics supervisor, and Barbara Smith, publications supervisor, all at the Division of Developmental Disabilities, The University of Iowa, for their efforts in this project.

I. Overview

We took Tammy to our local pediatrician when she was seven months old because she wasn't holding her head up. She was diagnosed as having cerebral palsy. A firm diagnosis at such an early age is fairly unusual, but it was backed up when we went for an examination at the university hospital. She is only three now, and her early diagnosis meant that we were able to get services right away through our community early intervention program.

Early intervention services were important for us. At about 1½ years the speech/language pathologist had Tammy begin using eye signals for communication. We hadn't been able to communicate with her at all before, and physically she was making very little progress. Suddenly she was functioning as a real person. She could let us know what she needed; she could make choices.

We went to an early intervention class once a week where Tammy received physical therapy and other services. While the children were with therapists, the parents had a support group meeting with the social worker. It was a tremendous help to have a place to let out our fears and frustrations. Parents of a normal child can complain to a friend when their kids are driving them crazy. It isn't acceptable for parents of handicapped children to complain.

Despite Tammy's early contacts with services, we need more. We know that Tammy will always be restricted physically, but she needs to develop the communication skills that will make her life meaningful. If she does, there is the possibility of her being mainstreamed in the schools. I don't know. The future is scary to think about for Tammy. We try to take one day at a time.

(Parent of child with cerebral palsy)

The years from birth to three for children with cerebral palsy are a time of great uncertainty, as Tammy's parents could attest. It is a time of uncertainty for the families, of course, but it is also a time of uncertainty for the professionals who provide the range of services that the family and child may need. The parents are anxious for "everything to turn out all right," and the professionals want to be a source of optimistic and yet realistic information and counseling to the family. However, the diagnosis of cerebral palsy indicates the possibility of motor movement disability resulting from irreversible, but nonprogressive, brain injury. The degree of disability varies from mild to severe, and the long-term outlook will only be revealed as the child develops and matures.

In most cases, during infancy and early life professionals cannot determine the exact nature of the damage nor can they predict to what extent a supportive, appropriate environment may compensate for it. This presents uncertainty in the adjustment process for the families and sometimes controversy among the professionals. What hope can health professionals, therapists, educators, and social workers hold out for the parents at the time a child is diagnosed as having cerebral palsy? How much hope is too much? Will professional "realism" get in the way of the progress that concerned parents can accomplish?

This monograph will address some of these issues for people concerned with developing services for children with cerebral palsy, whether as professionals or parents. This is not intended to be a therapeutic guidebook. Excellent sources of specific information required by therapists, nurses, physicians, and other care providers can be found in the appendix.

While exploring the needs of the child with cerebral palsy and appropriate ways to meet them, we will focus on the birth to three age group. While there is controversy over whether or not early physical therapy, for example, actually affects the eventual motor capacities of the child with cerebral palsy, there is little doubt that coping skills of all kinds, physical and emotional, for children with cerebral palsy and their families can be improved with good early intervention programs. Although established intervention programs with this age group are extremely varied, the basic needs of the child with cerebral palsy and some of the services designed to meet these needs will be outlined here. The etiology of cerebral palsy and the history of its management will first be discussed, followed by a review of service needs: prevention, early identification, and treatment programs, and social and educational ser-

vices designed to improve the child's quality of life. State systems for coordinating these services will then be discussed and examples of established programs will be described.

ETIOLOGY AND INCIDENCE

Cerebral palsy, sometimes called chronic nonprogressive neurologic injury, is a disorder of muscle control or coordination (motor output system) resulting from injury to the brain during its early stages of development (the fetal, perinatal, or early childhood stages). There may be associated problems with sensory input, such as vision or hearing deficits, central processing, such as communication, intellectual or perceptual deficits, and physiological health, such as constipation or seizures.

Brain injury may result from such events as maternal-fetal infection, bleeding into the brain during fetal life, or lack of oxygen at birth. Premature infants are particularly susceptible. Meningitis during early childhood or injury to the brain from falls or accidents also can cause cerebral palsy. The location of the damage in the brain determines both the type of cerebral palsy and the muscles which are affected.

With cerebral palsy, it is the brain's ability to control the muscles that is defective; the muscles themselves and the nerves connecting them to the spinal cord are perfectly normal. Since different types of birth injuries affect different parts of the brain, muscle control problems vary and can include spasticity (stiff, awkward movements), present in about 60 percent of cases of cerebral palsy, dyskinesia (involuntary, uncoordinated movements) present in 20 percent of the children, and ataxia (balance problems) present in 1 percent. Approximately 20 percent of affected individuals will have a combination of spasticity, dyskinesia, or ataxia with one type being dominant (Denhoff, 1976). The following terms indicate the part of the body that is involved:

► **DIPLEGIA**

Involvement of all four extremities (the legs more than the arms) and trunk (spastic type).

► **HEMIPLEGIA**

Involvement of the legs only (spastic type).

► **PARAPLEGIA**

Involvement of the legs only (spastic type).

► **QUADRIPLEGIA**

Involvement of both arms and legs, trunk and neck (any type).

Because events causing brain injury around the time of birth are seldom limited to small areas of the brain, they often result not only in muscle control (motor output) problems, but also in difficulties with sensory input, central processing, and health. A child whose primary difficulty is motor control, but who has problems in other functional areas as well, is classified as having cerebral palsy with associated problems. The associated problems can include:

SENSORY INPUT

VISUAL IMPAIRMENT

Approximately 50 percent (Donaldson and Walsh, 1966) of all children with spastic cerebral palsy have an eye muscle imbalance problem. Acuity (clearness of vision) deficits occur at a greater frequency than in the general population (Black, 1980).

HEARING IMPAIRMENT

Children with motor problems may spend a large percentage of their time in a recumbent position, causing persistent fluid in the middle ear and susceptibility to middle ear infections. This may result in varying degrees of conductive hearing loss.

CENTRAL PROCESSING

MENTAL RETARDATION

Around 50 to 75 percent (Cruikshank, 1976) of all children with cerebral palsy have some disability in intellectual function, ranging from mild to severe. This problem is seen less often with spastic diplegia.

PHYSIOLOGICAL DISORDERS

SEIZURES

The brain injury causing cerebral palsy often causes scarring during the healing phase on the surface of the brain, a source of chronic irritation that may precipitate seizure activity in 35 to 45 percent (some studies report 60 percent) of persons with cerebral palsy (Cruikshank, 1976). All types of seizures may occur.

Some persons with cerebral palsy have severe motor disabilities; others have barely detectable problems with muscle control. There is no universally used method by which physicians or therapists can objectively categorize patients as having mild, moderate, or severe degrees of motor dysfunction. Such estimates are usually made subjectively.

Cerebral palsy occurs in two infants in every 1,000 live births. Therefore, in a state with a birthrate of 150,000 infants per year, approximately 300 new cases (2×150) of cerebral palsy will occur each year. This is approximately twice as many children as will be born with meningocele, or Down syndrome, but only one-tenth as many as will experience mental retardation as their primary disability.

HISTORY OF MANAGEMENT

Thirty years ago, children born with cerebral palsy had experiences vastly different than they would today, as did their parents. The mother of a now-grown man of 33 reports not being terribly concerned about her son's premature birth, despite the fact that he weighed less than 3 pounds, had to have oxygen, and was in the hospital for almost two months. Although she was an educated and concerned mother, the correlation between early birth status and later development of cerebral palsy was not clearly understood then. "My daughter, born four years earlier, had also been premature and actually spent longer in the hospital because she had problems with digestion," the mother reports. "She turned into a normal and, in fact, rather precocious child." As time went on the mother became concerned about her son but not actually worried. Signs that she would look back on later included difficulty in pulling her son's legs apart when changing his diaper, his inability to pull himself up in his crib, and delayed onset of speech, although he seemed to understand what was being said to him. "I thought I was being a little silly to worry, and that I was unfairly comparing him to his sister, who was advanced for her age."

At age three, the boy was finally taken to a university facility for evaluation. The parents were totally unprepared for the diagnosis of cerebral palsy. They were devastated. "I had taken courses in education for handicapped children," the mother recalls, "and the diagnosis of cerebral palsy was a grim one."

Now a psychologist involved in special education, the mother looks back on many mistakes and frustrations in her efforts to

find services for her son. "My son's condition was not severe. He was mildly retarded. I knew from having lived with him for three years before the diagnosis was made that he was not a hopeless case. We formed a group, just on our own, to talk about our problems with other parents of children with cerebral palsy. The people that I felt really sorry for were the parents of the severely involved children. There was nothing for them then except institutionalization. They would spend a few years taking their children from doctor to doctor. Then they would decide to give the children up."

Services of all kinds have changed dramatically since that time. Important advances in newborn care during the past twenty years have greatly influenced the outcome of infants who are born prematurely or who are ill during the neonatal period. Obstetricians evaluate maternal risk factors and can use birthing centers equipped for high-risk deliveries. Neonatologists use highly sophisticated technology in neonatal intensive care units (NICUs) to provide levels of care unheard of twenty years ago. Infant follow-up projects periodically screen infants, and those with difficulties are cared for in programs organized under federal legislation such as PL 94-142 (Education for All Handicapped Children Act). Prevention and early identification programs have flourished with funding from Title V Maternal and Child Health (MCH) Block grants, State Crippled Children's Services (CCS) and other programs funded through the Office of Special Education and Rehabilitation Services (OSERS).

For the young child with cerebral palsy today, contact with health services will begin rather early. Martha and John Ramsey had two normal children when Martha became pregnant again. She was well-informed about prenatal care and attended classes at a local hospital which gave guidance on nutrition. This third pregnancy was proceeding normally until Martha went into premature labor two months early. A baby boy, Brian, was delivered at the private hospital in town and weighed 3 pounds, 2 ounces. He developed respiratory distress and the use of a ventilator was necessary. Because of these events and his small size, Brian was classified as a high-risk infant. Transferred to a major hospital with a neonatal intensive care unit, Brian did well without further complications, and after 7 weeks he had gained enough weight to be allowed to go home.

Because Brian was considered at risk to manifest a disability,

he was assessed periodically through a local community child health program. At the nine-month screening the little boy could not perform certain components of the tests usually accomplished by children his age. In addition, there were qualitative aspects of the neuromuscular examination that were of concern to the examiner. The Ramseys were immediately referred to a diagnostic center at a larger hospital with a unit for evaluating possible developmental problems. After the examination there, the staff told the Ramseys that Brian probably had cerebral palsy.

This was a difficult time for the Ramseys. The evaluation team at the diagnostic center, knowing the importance of early treatment in preventing some secondary complications of cerebral palsy, helped the Ramseys set up contacts with a local treatment team: a social worker, an occupational therapist, a physical therapist, and a home visitor. The Ramseys' local physician coordinated the efforts of the team. A private agency, United Cerebral Palsy, loaned Brian's family equipment needed to assist in feeding.

Before Brian was two years old, a wide range of professional people were already involved with his care. Some were directly associated with health services: physicians, dentists, physical therapists, nutritionists, occupational therapists, and nurses. Others were connected with social and educational services. Some of these services were paid for by the Ramseys. Some were publicly funded. Some were from private nonprofit agencies. Through a community childhood services program, professionals from social services, education, and health would meet together to plan for Brian's development and to offer comfort and support.

Developing a coordinated system such as the one which the Ramseys utilized is not an easy task. Difficult questions need to be addressed: What are the child's needs? Who will meet these needs? Who will pay for services?

While professionals and parents may share general goals for the child with cerebral palsy, the way the goals are translated into action may be quite different. Someone must see that the programs for the child are cost-effective. If certain dollars are spent on a child's program, will the child be more self-sufficient as an adult? Are the expenditures cost-effective for society? Parents as planners have different goals, such as happiness and the best possible quality of life for the child. The educational

planner is concerned with how education resources should be used for the child. Health service professionals, including nurses, therapists, nutritionists, dentists, and physicians, want to put the best of what they know into practice for the child in the early years to maximize early growth and developmental potential.

With cerebral palsy, as well as with many other disabling conditions, there must be a willingness to accept quality of life as a legitimate goal. When a child is kept out of an institution, when surgery is prevented or delayed, or when it is possible for a parent to return to work, there may be certain financial advantages. But care must not be judged on cost-effectiveness alone. Professionals, parents, and public service agencies must define the types and levels of services that should be made available to improve the quality of life for all children with disabilities, even when the immediate cost-effectiveness of some services cannot be demonstrated.

II. Service Needs

There are four main objectives in the management and treatment of cerebral palsy.

- prevention
- early identification
- treatment:
 - 1) to reduce the effects of the primary disability through facilitation of the normal developmental sequence and
 - 2) to prevent secondary complications or slow their progression
- improvement of the quality of life for the child and family

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The needs of affected children and their families must be differentiated from the services that are commonly provided. One need might be for proper seating while a child eats, a need traditionally met through activities guided by physical or occupational therapy services. But the fact that the child is receiving these services does not insure that the therapist (a) knows about the eating requirements of a young child with cerebral palsy, (b) knows about the need for proper seating during eating, (c) is aware of the proper techniques required to seat the child, or (d) is capable of teaching those techniques to a mother whose attention is on "more important things", such as teaching the child to walk.

We are focusing on "early intervention" services to meet needs, but the term can have different meanings. How early—soon after birth or sometime before school starts? Intervene with what? Intervention can be to promote the child's development when a birth defect or other physical or psychological injury alters the normal developmental process. But intervention can also be important when a child's development is at risk because of an environmental

problem, such as a nonsupportive family life. On occasion needs for both types of intervention are found in one child, and increased attention must be directed to matching the child's needs with the proper services.

PREVENTION SERVICES

Early identification of factors associated with undesirable pregnancy outcome, such as poor nutrition, alcohol abuse, or lack of good prenatal care, along with aggressive programs to deal with them, currently provide the best hope for preventing cerebral palsy. However, this area of prevention is also the most difficult to approach. Knowing the facts surrounding the birth of children who later develop cerebral palsy has not in itself lead to prevention of the condition. Prematurity (birth at less than 37 weeks gestation) is the event most often associated with the birth of infants who experience brain injury that leads to cerebral palsy. Effective methods for preventing early births, although the subject of investigations, have not been established. In addition, with as many as 40 percent (Hagberg, 1979) of all children with cerebral palsy, investigations of gestation, birth, and early health reveal no exact causes for the condition.

Modern neonatal intensive care has not had a clear-cut effect on the incidence of motor impairment in surviving infants. Although mortality among low birth weight infants has definitely decreased, it cannot be conclusively stated that neonatal intensive care has reduced the incidence of disability among survivors, despite certain optimistic recent studies (Kiely, Poveth, Stein, and Sussex, 1981). In fact, it was initially thought that reducing mortality among low birth weight infants would result in a higher incidence of handicaps among survivors (Drillien, 1958). In contrast to studies abroad (Hagberg, 1979; Davies, 1975), studies done in the United States do not show a decline in the incidence of cerebral palsy in recent years (Nelson and Ellenberg, 1978). There are some exceptions, such as studies reported by Franco and Andrews (1977).

Since the early 1970s, the technology and medical knowledge to support the infant "at risk" because of low birth weight or birth complications has vastly expanded. The care of these infants has been regionalized in centers equipped to provide modern care. But despite the improvements in care, the infants remain susceptible to long-term intellectual, communication, and physical dis-

abilities. Systems are now in place in some areas to 1) identify those infants who are at high risk; 2) provide follow-up examinations to identify the early signs of developmental disability; 3) enroll the children found to be disabled in appropriate early intervention programs.

EARLY IDENTIFICATION

Although not proven, it is widely held that early identification of motor dysfunction and early therapeutic intervention can, in some cases, reduce the severity of cerebral palsy. (Soboloff, 1981; Low, 1980; Denhoff, 1981). Dr. Lawrence Taft, an expert in the field of cerebral palsy, also supports early intervention because it can improve parent-child relationships, encourage the child to try new motor tasks, decrease parental "shopping," and lead to quicker and less painful adaptation by parents to the child's disability (Taft, 1981).

Some argue that it is inappropriate to tell parents their child may have a motor deficit at such an early stage. In most cases, however, such information is less a revelation than an acknowledgment of the parents' already existing concerns. Early recognition of motor problems allows parents to begin the normal grieving process sooner and begin focusing on the child's strengths rather than wondering about the deficit.

Theoretically, how soon can or should a child with cerebral palsy be identified? Depending upon the severity of the motor impairment, the diagnosis may be possible as early as the first month of life, but, more commonly, it becomes evident during the second half of the first year. In a majority of cases, experienced clinicians should be able to detect moderate to severe cerebral palsy by nine to twelve months of age. However, children with very mild motor dysfunction may not manifest the problem until the age of two or three.

How are infants with cerebral palsy identified? The most likely individual to first suspect cerebral palsy is the physician. There has been a growing movement in this country to make sure that physicians can recognize the early signs of cerebral palsy and that they understand the benefits of early treatment. During the first year of life, most children have repeated contacts with physicians or health care providers associated with physicians for routine health supervision and acute illnesses, offering the opportunity for a longitudinal view of the child's development. Delay

in attaining motor milestones is an indication of possible cerebral palsy. The physician who performs a careful history and physical examination at each visit will notice the warning signs, which most often include

- Delay in attaining developmental landmarks
- Asymmetrical motor patterns or movements
- Abnormalities in tone—hypotonia or hypertonia
- Associated problems with irritability, feeding and constipation
- Growth failure or delay

Programs for early identification of children with disabilities are fairly new. The Maternal and Child Health and State Crippled Children's Program provisions of Title V have played a major role in promoting prevention, early identification, and intervention programs, particularly for high-risk children. The Maternal and Child Health approach relies on a developmental model of interdisciplinary comprehensive health care in a family-centered context. Federal funding support is provided by the states through the Title V block grant program for activities specifically related to the high-risk infant.

In 1967, Congress passed amendments to the Medicaid Act (Title XIX) initiating a program of Early Periodic Screening, Diagnosis, and Treatment (EPSDT) for Medicaid eligible children. Unlike previous federal medical assistance programs, EPSDT provided screening and early detection services in addition to payment for health care when eligible individuals were sick. This program has had mixed success in reaching its intended target population. It is, however, an example of an approach to the early identification and treatment of health and developmental problems (Elles and Cross, 1977). States devised their own plans to implement the federal mandates and, in some cases, strengthened the provisions of the federal laws. For example, some states require screening and evaluation to ascertain whether a child is in need of special services in order to benefit from an educational program. While federal laws have mandated identification and initiation of services for various developmental disabilities, individual states' responsibility for very young children has varied greatly. Some provide identification and therapeutic services to children beginning at age five, others at age three, and a few from infancy. The most comprehensive and influential

special education legislation is PL 94-142 (Education for All Handicapped Children Act of 1975), which provides federal funds to help states pay for the education of all handicapped children. PL 94-142 services do not require states to begin intervention services until age three, although states are not prohibited from providing services from birth.

Privately endowed and volunteer supported organizations have also been active in early identification programs, including the National Association for Retarded Citizens, the National Easter Seals Society, United Cerebral Palsy Association, and the National Foundation. These agencies and a variety of local community groups have organized "child find" efforts. Private foundations, such as the Robert Wood Johnson Foundation, also fund projects to provide services or training functions for those screening or serving young disabled children and their families.

The screening used with these programs is designed to identify the *possible* presence of an impairment, not to establish a diagnosis. Children identified in a screening go on to a more extensive evaluation in which the presence of the condition is confirmed and a management plan developed. This evaluation process involves health providers, therapists, and educators.

Although we have emphasized that improved quality of life for children with disabilities should be the main goal of early identification, the financial motivation for making early intervention programs work is also growing. A recent study by Wood (1981) showed the positive effect that early intervention programs can have on later educational costs for the child. Further studies will be required to validate these extremely encouraging results in other states and under other administrative schemes.

TREATMENT

An effective treatment program is one that takes into consideration the heterogeneity of cerebral palsy. No child with this disability has the same family or community environment, physical involvement, intellectual ability, or personality. The challenge is to match the unique needs of the individual with appropriate professional and family skills, using the best combination of financial and personnel resources in the community.

Some of the reasons for early treatment of cerebral palsy are to initiate proper handling techniques, to promote the development of communication skills, to develop more normal patterns

of movement before abnormal patterns are fixed, and to prevent joint contractures, while postponing or eliminating the need for orthopedic surgical procedures.

Currently acceptable therapeutic approaches for the disability include the neurodevelopmental model advocated by the Bobaths (1980), the goals of which are to inhibit primitive reflexes and facilitate postural reflexes in order to achieve purposeful motor activity. An eclectic approach may also be used in which the unique characteristics of a child's disability are identified and treatment techniques are derived from a number of sources and may include range-of-motion exercises, inhibition of abnormal tone, proper positioning, and facilitation of functional movement patterns.

Problems that may accompany the primary diagnosis of cerebral palsy are important to consider in assessing the treatment needs of affected children. Tablan (1970) studied 333 individuals with cerebral palsy and found that very few children with cerebral palsy have a motor disability alone. Twelve percent had two disabilities, 40 percent had three, 32 percent had four, and 16 percent had five or more. Additional disabilities can include speech problems, visual disturbances, hyperactivity syndromes, mental retardation, deafness, and perceptual problems. In addition, infants and young children with cerebral palsy may show abnormal patterns in growth, eating, sleeping, and bowel habits. A child may also have increased frequency of medical problems such as seizures, aspiration pneumonias, or of infections, such as otitis media (middle ear inflammation), which require frequent consultation. These problems impose additional stress on families who already find it difficult to cope with a disabled youngster. The complex care needed may tax the family's financial resources as well.

THE INTERDISCIPLINARY TEAM

Given these potential management needs, many professionals become involved in the care of the child, including the following: physicians (including pediatricians, family practitioners, neurologists, neurosurgeons, psychiatrists, orthopedic surgeons, physiatrists), dentists, physical therapists, occupational therapists, speech and language pathologists, psychologists, nutritionists, nurses, educators, and social workers.

These professionals are often organized into an interdisciplinary

nary team at a diagnostic center or in community early intervention programs. This organizational scheme can be helpful, since team members share responsibility and depend on each other for their own success, and they develop an interest in the child and family beyond their immediate specialty. In the interdisciplinary process, it is assumed that the results, both in terms of information obtained and services provided, are greater than the sum of what each discipline could provide independently. There is more economical use of professional time, and the child and family receive the benefits of a coordinated, comprehensive approach to the problems.

An individual or agency needs to be designated to coordinate the varied services. This may be the child's primary physician, a school-based service for the disabled, a public health nurse, a local agency that provides most of the ongoing services, or a referral center. Some of these coordinating systems will be discussed in Section III.

PRIMARY, SECONDARY, AND TERTIARY CARE

With the increased interest in providing services locally, the tertiary care center is becoming more and more the center for evaluations and for advisory care on particularly complex problems. Most children with cerebral palsy will be seen at least occasionally at a tertiary center. In this section, we will discuss the roles of staff members on an interdisciplinary team and how the tertiary and primary levels interact.

While the terms primary, secondary, and tertiary care are used widely in descriptions of health services, the function of each level will vary greatly with the medical service structure of a particular state or area. Primary medical care can be provided by a local pediatrician or family practitioner or in a clinic or health maintenance organization. At the primary care level, the related services which the child with cerebral palsy will probably need should be provided in coordination with the medical services. Often, however, they are not. Physical, occupational and speech/language therapy, and psychology services are usually provided through the schools, and counseling by social service agencies. At the tertiary facility, usually a large medical facility and often a university-affiliated teaching hospital, generally all the disciplines required for a complete developmental evaluation of a child will be brought together in one location and there will be

some coordination of the evaluation among the "team specialists." Diagnosis and management suggestions made at the tertiary level are referred back to the primary care personnel. The secondary level is between the other two in terms of resources and sophistication and attempts to focus community resources directly on the patients with the most complex needs. Care classified as secondary level may not exist in some areas.

With some conditions, extensive, highly technical medical care for treatment and diagnosis is needed from the time of the child's birth, and this is usually provided at a tertiary center. Experience is critical to making the diagnosis of cerebral palsy, since specific blood tests or radiographic techniques are usually involved only in eliminating other conditions as a source of the child's problem. Although the primary physician may suspect cerebral palsy, the tertiary team often confirms the diagnosis or suggests a different diagnosis. Tertiary personnel will often be perceived by parents and referring professionals as "final judges" on diagnoses and therapy recommendations.

Physicians serving in tertiary level health care programs should also serve as role models for other physicians in training who have not had the experience of working in an interdisciplinary manner with nurses, therapists, and others. The relationship of physicians to colleagues on the team can provide lessons in cooperation that will help improve the quality of service provided to the child and parent. Descriptions of the roles of some of the key interdisciplinary team members follow.

The **physician** member of the interdisciplinary team is responsible for establishing the primary medical diagnosis and helping the family understand its immediate and long-term implications. In establishing the diagnosis, the physician must determine the absence of many other genetic, metabolic, neuromuscular, or structural brain abnormalities that have features similar to cerebral palsy. It is imperative that physicians who assume this responsibility are well trained in the natural history of this condition and that they are able to interpret family histories and perinatal events, perform a comprehensive developmental and neuromuscular examination, appropriately select laboratory and radiographic tests, and involve other medical specialists as needed. The physician must perform in a technically satisfactory manner, but must also interact and communicate well with the family. Understanding the effects of the disability on the feeding, sleeping, elimination,

and other functions of the child is important.

The **dentist** on the interdisciplinary team can be a source of advice and service to this population. Although children with cerebral palsy may not have dental problems different from other children, parents often have difficulty understanding the dental care needs of children under three years of age. Studies have estimated that as high as 90 percent of children with neuromuscular disorders have malocclusions, which means that children with cerebral palsy may need special attention in this area.

Speech/language pathologists and audiologists are commonly involved with the child with cerebral palsy from early diagnosis on. The specific services performed at the tertiary and primary level will depend to a large extent on what is available locally. Early contact may be the starting point for a serial assessment that will establish level, pattern, and rate of development in the speech and language areas. Critical to an understanding of the child's intervention needs will be an assessment of possible disparity between receptive language and expressive language. Is, for example, the child understanding well, but because of motor problems not able to use expressive language? Children with cerebral palsy who also have some level of mental retardation will have a language deficit. Do these children also have a communication deficit related to their motoric disability? While it is important to stay as flexible as possible in expectations of language development for this very young age group, intellectually normal children who will need nonoral augmentative communication systems, such as a language board, may be identified as early as twelve to eighteen months of age. Skills needed to use these systems can then be developed. The speech/language pathologists must make sure that early intervention strategies do not interfere with the parents' often intuitively appropriate stimulation and encouragement of the child's language development.

Recommendations for local care should be based on a good knowledge of what is available. An early childhood specialist, for example, may be a greater asset in some cases than several specialists. In cases where there are no local early childhood specialists, parents can learn about the activities they can use naturally to stimulate the child's language development and be encouraged to amplify these. The focus of recommendations at this age should be on providing models for communication and on building up the parents' confidence in their abilities to provide a good environment for the child.

Communication should be encouraged between tertiary and primary providers, although channels may not always be in existence in this therapy area. Speech/language pathology services are usually in the schools, but not all school systems have programs that reach to this early level. In cases where no early services exist, the tertiary center may take a more active role in communicating with the parents and serving as consultants for them.

Like speech/language pathologists, **occupational therapists**, who work with cerebral palsied children in the birth to three age group should enhance the family's natural abilities to help the child develop skills. The occupational therapist has two main areas of assistance to offer. The first relates to the family's life-style and ways to make daily routines easier. The other is therapeutic and involves ways to help the child become more independent, do things more normally. In serving the needs of the family, the occupational therapist deals with rather personal parent-child activities. Parents feel they are supposed to know how to feed and bathe their baby. Although the parents may understand they are dealing with a child with special needs, instruction in these basic areas of care must be done with special understanding in order to maintain the parents' sense of competence.

The occupational therapist can help the family members position children for routine activities, such as feeding and bathing. The special positioning techniques can make routines that have become sources of struggle and frustration into more normal experiences. Proper positioning can prevent choking and help prevent the development or advancement of back deformities. Positioning techniques can also make it possible for children to do things for themselves, increasing the chance for independence as they get older.

Physical therapists assist the child with cerebral palsy in three major areas. They can 1) help facilitate management for parents in such areas as positioning, 2) help the child learn to relax and function better in self-management, and 3) provide therapy that can prevent muscles and joints from losing movement ability. At evaluations, the physical therapist is involved in watching for the stages of development the child is approaching so that new activities, assistive devices, or bracing can be recommended at appropriate times.

The tertiary-level physical therapist must coordinate recommendations with what is known about the local resources. Physical

therapy is in particular demand by parents because it is active and parents can see something very concrete being done for their children. The physical therapist should encourage parental involvement in therapy as much as possible and make sure that parents have a realistic understanding of the effects of therapy.

The **social worker** acts as both a counselor and a financial consultant with the families of children with cerebral palsy. Helping families understand and plan for their added financial responsibilities can be a complicated task. While it is desirable to have as much of the child's care as possible done on an outpatient basis, many third-party payers do not yet cover outpatient services. Families who do not qualify for Title XIX or SSI funds may at times be drastically affected financially, due to the expenses related to checkups, transportation, tracing, or vision problems.

At the time of the initial diagnosis, the social worker at the tertiary center may do much to help prepare the family psychologically for the long-term efforts ahead and can assist the family in making contacts with community services. Working with the interdisciplinary team, the social worker may help the parents sort out and understand what services the child really needs, as opposed to what parents have heard other children with disabilities are receiving.

The **nurse**, serving in an integrating role, often is able to help the family understand the health and medical aspects of cerebral palsy while also providing specific nursing functions. The nurse can provide assistance in dealing with many management concerns, such as irritability, irregular sleeping patterns, breast or bottle feeding, and solid feeding routines.

The young child with cerebral palsy may have special nutritional needs because of the growth problems often associated with the condition. The **nutritionist** works closely with the occupational therapist, physician, and nurse to understand the positioning, hand function, temperament, and activity level of the child so that appropriate sources of calories, fluids, minerals, trace elements, and vitamins can be presented in an acceptable manner. This cooperative approach to solving feeding problems is often the key to having families feel secure with the team in other rehabilitative areas. Children with cerebral palsy have widely varying dietary and nutritional requirements depending on their muscle control problems. Feeding problems may be evident in early infancy. Some children will continue to have difficulty with sucking, swallowing, and chewing. Children with dyskinesia have constant in-

voluntary motion, which requires extra calories in order to maintain adequate growth and weight. This uncontrolled motion makes eating a difficult task for these children. Fatigue of both the child and the feeder may make it difficult for the child to ingest enough food to meet caloric and nutrient requirements for growth. On the other hand, children with spasticity are relatively inactive and thus have a lower caloric requirement. Excessive weight gain due to limited activity must be prevented so that obesity does not become an additional impediment to the child's mobility. Some children with cerebral palsy may be given medications that interact with nutrients and thus require special dietary management.

Psychologists not only evaluate the cognitive and intellectual skills of children with cerebral palsy, but are also involved in assessing temperament, learning styles, attending behaviors, and other factors that assist therapists, nurses, and physicians in planning and carrying out treatment programs. The psychologist on an early intervention team often collaborates with the social worker to help parents and other family members adjust to having a child with a disability in the family.

An **early childhood specialist (educator)** is an individual with training, either at the bachelor's level or master's level, in selecting and using appropriate language, cognitive, and motoric activities to enhance the development of infants and young children. Many of the strategies selected by early childhood specialists help parents and care givers to understand the infant's developmental sequence. Early childhood specialists' training includes work with disabled infants, as well as those who are judged to be at risk because of social or biologic factors, to develop disabling conditions. Many are also employed in day-care centers and other facilities for children who are experiencing normal development.

COMMUNITY SUPPORT SERVICES

The availability of support services for families varies greatly with the community. Even when services are available, families may not take advantage of them because they either do not know about them or feel too uncomfortable or proud to ask for the help offered. A social worker, local physician, or other person having good rapport with the family should both inform families about financial and counseling resources and encourage their use. One of the services available may be a parent support group, which gives the families an opportunity to share their concerns

with others in similar situations. Easter Seals, United Cerebral Palsy, or other community service agencies may be among the groups that have some assistance to offer, including limited financial help for purchasing or renting equipment.

LINKS WITH EDUCATIONAL SERVICES

States differ widely in the educational services offered for the birth-to-three-year-old group. Some states have no services reaching this early age group, while others have mandated extensive service systems which may include therapies offered by a range of professionals from the moment the child is identified as having cerebral palsy.

Services offered may include both home-based and center-based services. Each has advantages and disadvantages. Both types of programs are based on the belief that early intervention has long-term beneficial effects for the child. Home instruction can include visits from several different therapists on a regular basis or home visits from one teacher or early childhood specialist who helps parents with activities to encourage the child's movement, communication, and comprehension development. The advantages of home-based programs are that therapists work closely with the family in establishing and continuing therapy routines and that transportation costs can be reduced for the parents. Some feel that disadvantages are that the services are only infrequently provided, and while they have intimate contact with the families, they may sometimes not involve and educate the families enough in the management of the child, but simply carry out the routines themselves.

At center-based programs the children are brought to a school or other facility for therapy. Many center-based programs have activities, such as group discussion or counseling for the parents while the children are in therapy. The center-based programs serve as a form of respite care for families who otherwise receive no break from care of their children. The disadvantages of the center program may be that there is little involvement on the part of the parents in the therapy, and transportation, if not provided by the agency, may be difficult for some parents.

While health professionals are often involved in referring children to the educational programs, a close tie between health and educational professionals must be maintained. Often young children with cerebral palsy have experienced associated physiologi-

cal disabilities for a long period of time and may continue to be medically fragile—particularly susceptible to infections and less able to "bounce back" after an illness.

TRAINING FOR HEALTH PROFESSIONALS

Adequate services for children with cerebral palsy require well-trained professionals. There is no doubt that all professionals working with young disabled children must first have a solid understanding of normal child development, coupled with varied experience in evaluating abnormal and deviant developmental patterns of children. All of these skills must be learned in clinical settings using the interdisciplinary process and should be designed to improve communication among the interdisciplinary team members. In-service programs should be designed to meet the needs of those practitioners who have not had the benefit of such approaches during their formal training. It would appear that such programs utilizing a "practicum" approach with clinical experiences enhancing didactic presentations would be of the most benefit for future members of interdisciplinary teams.

III. Coordination of Services

Problems associated with coordination of services become clearly dramatized when we deal with children birth to three and with a disability such as cerebral palsy, which may involve an extremely wide range of service needs. The diagnosis of disabilities in the infant and very young child has generally fallen to the health care professionals because of the nature of disabilities identifiable at this age. However, therapy for the children now more often comes from the education arena. This may cause conflict because of poor communication and coordination. Poor communication becomes a very real problem. With cerebral palsy, the question of "Who is doing what for whom?" can be a complicated one. Problems of duplication of services may be especially acute in areas where there are many active early childhood programs.

What kind of system will meet service needs and coordinate a particular state's or community's resources in the most efficient way? This question is being asked in many areas around the nation, and as time goes on, well-defined systems of coordination will be developed that can serve as models. No one model will apply to the nation as a whole. To work effectively, these systems must take into consideration local features, such as an urban or rural population, and very importantly, the kinds of health, education, and social services already functioning. For efficiency and public acceptability, programs must build on these already existing segments.

In this section, rather than offer a single hypothetical system

for coordinating early intervention services, we will outline some of the successes, problems, and ideas expressed by those involved in coordinating ongoing programs.

REGISTRY

The question of who is doing what for whom is being addressed rather dramatically in one state through the creation of a computer-assisted registry used jointly by the health, educational, and social service systems. A child identified as being delayed in an early intervention screening by the education services would be put in the registry. If the child is later seen by health providers, a check could be made with the registry to determine which services the child is already receiving or has received in the past. As an example of how the system has helped, a child with cerebral palsy recently put on the registry was found to have appointments with three different occupational therapists in one week. The mother assumed that these appointments were all part of a plan, when they were in fact a result of lack of communication.

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Computers may be used as communication devices between service systems as well. For example, a request from social services that a child be seen by health services would remain in the computer until the child is evaluated by members of a health services unit. Future plans may include tying this service registry in with a birth defects registry and a high-risk pregnancy registry.

The potential dangers of such a far reaching system are also becoming evident. Currently, the health care sector is often reluctant to enter into the system. "This is because," says one physician, "we are most concerned with the problems and possible legal liabilities involved in confidentiality violations." For some, also, such a system may seem too "big brotherish."

DECISION-MAKING

Some states have legislative mandates that set up systems for coordinating the early intervention programs for disabled children. This reflects an important kind of state commitment, as it defines the *process* of decision making and planning rather than the specific features of the early intervention program. This state previously did not have educational services reaching below age three. A council, established by law, is made up of representatives from the Department of Health, the Department of Mental

Health and Mental Retardation, the Department of Human Resources, and the Department of Education, plus one public appointee. The group is responsible for policy making. The head of the State Crippled Children's Services early intervention program meets with the council, usually on a monthly basis. Four times a year, an advisory panel, consisting of nurses, consumers, physical and occupational therapists, and parents, also meets. Local physicians are primarily used in the program, but must first be approved, both as to their expertise and their agreement to a fee schedule. Because of the rural nature of this state, public health nurses are the main case managers for families brought into the early intervention program, although social workers may also be involved. Care in one of the state's eight tertiary facilities is followed up by assignment to one of the approved physicians. This program takes the place of a much smaller early intervention program that was only available to low-income children. Now the mandate covers children at high risk for motor or neurological delay, regardless of their family's income.

PREVENTION PLANNING

Some state and community plans make a more substantial commitment to prevention areas. As one state planner says, "The main goal in the prevention of cerebral palsy is to decrease the birthrate of very small babies." While important factors associated with low birth weight and premature infants are known—including young maternal age, nutritional inadequacy, smoking, and alcohol consumption—coordinated programs which maintain an active prevention program are not well established. Because they must often address socioeconomic factors as well as personal habits and life-style, it is difficult to measure the success of prevention programs, even more difficult than it is to establish the success of early intervention programs for children who already have problems. Efforts at public education need to be built into early intervention programs, and effective ways of going about this should be shared.

DECISION-MAKING SYSTEMS

Who should put together an early intervention plan? In one state where early intervention services are managed through the State Crippled Children's Service, there are three levels of decision making. Dealing directly with the child, a team of professionals is involved with developing two plans for the child, one a

diagnostic plan and the other a functional individual plan. A public health nurse, or occasionally a social worker, acts as case manager. Depending on the particular needs of the child, a nurse, physician, nutritionist, social worker, orthopedist, and neurologist may all be involved in decisions. The parent is also involved and must sign the plan before any funded services can be offered. An MCH advisory committee meets four times a year to make recommendations on how early intervention monies should be spent. The committee includes representatives from the state DD council, from its Crippled Children Service, school and health agencies as well as from MCH. In addition, an advisory board—which includes representatives from the March of Dimes, Easter Seals, Elks Club, and the Commission for the Handicapped—interacts with this committee in a lobbying capacity.

PLANNING FOR PROFESSIONALS

The effect that communications between professionals and parents has on parents' expectations of their children and of the service system is important to the comprehensive service system. Can the system provide what is actually needed by the child? What role should professionals, parents, and planners play in establishing what this is? It is a delicate question and one that cuts to the core of our knowledge about early childhood development.

Most planners of early intervention programs believe that increased efforts at raising the level of professional awareness and expertise must be made in the future. Several states with early intervention plans have built training into their programs. One University Affiliated Facility (UAF) put on twelve workshops around the state to train nurses to recognize developmental delays. Rather than relying on lectures, actual clinic patients were used as demonstration models. Other UAFs train physicians and therapists in evaluation and treatment modalities. Another state with a strong commitment to early intervention trains child development nurse specialists, stressing identification and home-oriented therapy, in an attempt to improve coverage for the birth-to-three age group in remote areas. In-service training for practicing physicians has been more difficult, and as one planner suggests, the physicians that participate are often the ones that are already involved in early intervention in some way. Clearly, the health sector must be involved in making their professionals knowledgeable participants in early intervention plans.

IV. Summary

Children affected with cerebral palsy and their families must adjust to a life of coping with whatever degree of disability is part of the condition. While some argue that early intervention programs are not justified in terms of their corrective capacities, it is the contention of the authors that a system that uses cures as a service criterion is off the mark. With cerebral palsy and many other disabling conditions, we must consider both the humanitarian goal of improving the quality of life for affected children and the societal benefits from enabling families and individuals to maximize their ability to cope and their potential for leading full, productive lives.

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While increasing interest is being focused on the early years of development, the service delivery system for children with cerebral palsy must become more sophisticated and it must also focus on the family unit, not just on the disabled child. We in the health care sector need to learn more about the interrelationships between normal and abnormal development in the early years, and we need to turn our improved knowledge into identification and therapeutic strategies for improving the outcomes of children with cerebral palsy. At the same time, health professionals must become active participants in a coordinated system that will use health, social service, and educational resources efficiently for this early age group.

As one planner and promoter of early intervention programs states, "The main thing that we are doing during these first three years is to raise the family's coping skills. Family members need to care about each other, and yes, we can affect their ability to do this by providing appropriate professionals to help make the care of their disabled child easier. Will there be a payoff for society in

having families better adjusted to caring for children with cerebral palsy? We think the answer is definitely yes."

References

A Study of the Health of Iowa's Children and Youth, Iowa Chapter of the American Academy of Pediatrics, September, 1979, pp. V-140.

Black, P. D. Ocular defects in children with cerebral palsy. *British Medical Journal*, August 1980, p. 487.

Bobath, K. A *Neurophysiological Basis for the Treatment of Cerebral Palsy*: Clinics in Developmental Medicine. No. 75. Philadelphia: Lippincott, 1980.

Davies, P. A. and Tizard, J. P. Very low birth weight and subsequent neurologic defect (with special reference to spastic diplegia). *Developmental Medicine and Child Neurology*, 17:3, 1975, p. 3-17.

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Denhoff, E. Medical aspects. *Cerebral Palsy: A Developmental Disability*, W. Cruickshank, (ed.) Syracuse: Syracuse University Press, 1976, p. 30.

Denhoff, E. Current status of infant stimulation or enrichment programs for children with developmental disabilities. *Pediatrics*, 67, No. 1, 1981, p. 32-7.

Donaldson, D. and Walsh, F. Neuro-ophthamology in children. *The Pediatrician's Ophthalmology*, Liebman and Gellis, (ed.). St. Louis: C. V. Mosby, 1966, p. 199.

Drillien, C. M.: Growth and development in a group of children of very low birth weight. *Archives of Diseases of Children*, 33, 10, 1958.

Elles, N. E. and Cross, L., (eds). *Planning Programs for Early Education of the Handicapped*. New York: Walker Inc., 1977.

Franco, S. and Andrews, B. Reduction of cerebral palsy by neonatal intensive care. *Pediatric Clinics of North America*, 1977 24(3) 1977, pp. 639-49.

Hagberg, B. Epidemiological and preventive aspects of cerebral palsy and severe mental retardation in Sweden. *European Journal of Pediatrics*, 130, 71, 1979, pp. 71-78.

Kiely, J., Paneth, N., Stein, Z., and Susser, M. Cerebral palsy and newborn care II: Mortality and neurological impairment in low-birth weight infants. *Developmental Medicine and Child Neurology*, 23(5), 1981, p. 650.

Low, N. A hypothesis why "early intervention" in cerebral palsy might be useful. *Brain and Development*, 2, No. 2, 1980, pp. 134-35.

Nelson, K. and Ellenberg, J. Epidemiology of cerebral palsy. *Advances in Neurology*, Vol. 19, Bruce S. Schoenberg (ed.) New York: Raven Press, 1978, p. 421-35.

Soboloff, H. Early intervention—fact or fiction? *Developmental Medicine and Child Neurology*, 23, 1981, p. 261-6.

Taft, L. Intervention programs for infants with cerebral palsy: A clinician's view. *Infants at Risk: Assessment and Intervention*. C. Caldwell Brown, (ed.) Johnson and Johnson Baby Products Company, 1981, p. 74.

Tablan, D. J. Clinical analysis of the brain damaged child. An analysis of 333 cases in the Philippines. Paper presented at the International Society for Rehabilitation of the Disabled. Dublin, 1970.

Wood, M. Cost of services. *Early Intervention for Children with Special Needs and Their Families: Findings and Recommendations*. Jay Swanson, (ed.), Monmouth, Oregon: Westar Publishing Co., 1981.

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Appendix

Bobath, B. and Bobath K. *Motor Development in the Different Types of Cerebral Palsy*, New York: William Heinemann, 1978.

Connor, F. P., Williamson, G. G. and Siep, J. P. (eds.) *Program Guide for Infants and Toddlers (With Neuromotor and Other Developmental Disabilities)*. New York: New York Teachers College Press, 1978.

Finnie, N. *Handling the Young Cerebral Palsied Child at Home*, New York: E. P. Dutton-Sunrise, 1975.

Haynes, U. *A Developmental Approach to Casefinding (With Special Reference to Cerebral Palsy: Mental Retardation and Related Disorders)*. DHEW Pub. # (HSA) 79-52 '0, Washington, D.C. Government Printing Office, Washington, D.C. 1980.

Joel, G. S., *So Your Child Has Cerebral Palsy*. Albuquerque: University of New Mexico Press, 1975.

Levitt, S. *Treatment of Cerebral Palsy and Motor Delay*. St. Louis: C. V. Mosby, 1978.

Safford, P. L. and Arbitman, D. C. *Developmental Intervention with Young Physically Handicapped Children*. Springfield, Ill.: C. C. Thomas, 1975.

Samilson, R. (ed.) *Orthopedic Aspects of Cerebral Palsy*. Philadelphia: J. B. Lippincott, 1975.

Scherzer, A. and Tscharnuter, I. *Early Diagnosis and Treatment in Cerebral Palsy*. New York: Marcel Dekker, 1982.

Thompson, G., Rubin, I., and Bilenker, R. *Comprehensive Management of Cerebral Palsy*. New York: Gruene and Stratton, 1983 (in press).

